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BURDEN OF BURULI ULCER: HOW AFFECTED HOUSEHOLDS IN A GHANAIAN DISTRICT COPE

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ABSTRACT Buruli Ulcer (BU) is economically burdensome and socially stigmatising. We examined the burden of BU and the strategies commonly adopted by households in a Ghanaian district to cope with it. Respondents for the study were conveniently sampled using data from a BU unit within the District Health Centre. Adult BU patients and caretakers of minor patients (aged less than 15) who had reported for care within the past year were interviewed. A semi-structured questionnaire was used for the interviews. The staff in-charge of an international NGO with services to BU patients in the district was also interviewed. The disease was associated with poor rural households with mean annual incomes of the equivalent of USD 490.70 or less. Other costs and stigma associated with the disease posed a great burden on the already poor households we studied. Households adopt coping strategies, including sale of assets, reduction in farm sizes, and avoiding people, all of which are potentially risky for future sustainability.

Key Words: Buruli ulcer; Coping strategies; Stigma; Poverty; Ghana.

BACKGROUND AND TRANSMISSION OF BU

Buruli Ulcer (BU) can no more be said to be a new disease in the world. In fact it has been around as far back as the 1800s, if not earlier. It is rather surprising that considering the rate at which it is spreading around the world, probably faster than imagined, very little is known about its mode of transmission. The causative organism of BU was identified to be a *mycobacterium ulceran*, not much else is known (WHO, 2006). BU remains one of the most dreaded diseases humans have encountered in the recent centuries since it was discovered. The WHO has noted that it is the third most common mycobacterial infection in humans (WHO, 2006). The disease is more prevalent in the tropics and the sub-tropics. In Africa, even though it was first observed in eastern Africa (Uganda), it is more endemic in the western wing and particularly more prevalent in Benin, Cote d'Ivoire, Ghana, Guinea, Liberia, Nigeria, Sierra Leone and Togo (WHO, 2006). According to WHO's statistics, Ivory Coast recorded 24,000 cases, Ghana recorded 11,000, and Benin has 7,000 confirmed cases (WHO, 2006).

In Ghana, even though it is said that BU was first noticed in 1971 (Bayley, 1971), Ghanaian health care officials indicated that the disease was diagnosed as far back as 1969 (Montoro et al., 1997). The disease has engulfed the whole country with a national prevalence rate of 20.7 per 100,000, which is about two times the prevalence rate of leprosy in the country (9 per 100,000). In the most

endemic districts, the prevalence rate is however higher (150.8 per 100,000). Active cases have been identified in all ten regions of the country and were present in 90 out of the 110 districts in the country as of 2002. It is more prevalent in the southern belt: Ashanti, Central, Western and Eastern Regions (Amofah et al., 2002).

The disease largely occurs in people who live and work close to rivers and stagnant bodies of water (Vincent et al., 2004). However unlike malaria and other tropical diseases, its mode of transmission is unclear up to date. Earlier evidence suggests that aquatic insects (*Naucoris* and *Dyplonychus*) may be involved (Vincent et al., 2004). But here still the precise role of these water-insects, flies and mosquitoes is not known. Van der Werf and others (1999) also suggested that humans become infected through contact with the swampy environment. Again the human-environment interaction suggested is not clear. Person-to-person transmission of the disease has not been established either, even though in some cases patients had relatives who were also infected (Muelder & Nourou, 1999).

The disease affects all age groups, although children under the age of 15 years (range 2–14 years) are predominantly affected (WHO, 2004). Several studies have also suggested that there is no sex difference in the distribution of BU infection (van der Werf et al., 1999). Even though the disease can affect any part of the body, it is more often found on the extremities (especially the limbs) as compared to the other parts (Barker, 1973; Hospers et al., 2005; Ndobe & Ghotbi, 2008). Some researchers have gone further to note that the lower limbs are more likely to be affected than the upper limbs, and this may be because the lower limbs are frequently in contact with soil, water, plants, and insects (Ndobe & Ghotbi, 2008).

The average incubation period of BU is from two to three months (Portaels et al., 2009). During this period the disease goes through a wide spectrum of clinical transformation mostly associated with the time between the onset of the disease and when the patient seeks health care for diagnosis. Clinically, the disease can be divided into pre-ulcerative stage (papule, nodule, plaque, and diffuse oedema) and ulcerative stage, which may be represented by ulcers smaller than 5 cm and ulcers larger than 5 cm (Portaels et al., 2001; Portaels et al., 2009; Boleira et al., 2010). The initial stages of the disease, which normally varies from weeks to months, may cause subclinical symptoms or even develop an asymptomatic profile, thus remaining latent (Boleira et al., 2010). It is more common in the initial stages for a patient to notice a small pustule, often attributed to insect bites which may last for about a week depending on the immune system of the person. This stage of the disease often does not make the patient seek medical assistance (Boleira et al., 2010). The next phase of the pre-ulcerative stage continues with painless and mobile skin nodule less than 2 cm in diameter.

Later, the patient may have the latent manifest clinical symptoms, such as plague and undermined oedema. Plaques are raised and hard, but still painless, with a certain degree of depigmentation or spotted erythema. They can have more than 2 cm of diameter, possibly reaching 15 cm. They can develop into large ulcers with irregular borders (Boleira et al., 2010). When there is only one oedema, the profile is more diffuse, and with poorly demarcated borders. The ulcerating stage develops due to perforation of the necrosis above the epidermis. Initial

ulcers may remain small, with 1 to 2 cm of diameter or become larger (larger than 5 cm) and destroy the skin around them. The borders of ulcers are often depigmented and their background necrotic. The disease can also be present with a large area of marked indurations, diffuse oedema in the legs and arms or a well-demarcated plaque (WHO, 2007).

If the disease is identified early, treatment is relatively easy. The use of rifampicin and streptomycin is noted to have a positive impact on treatment outcomes (Amofah et al., 1998; WHO, 2004; Etuaful et al., 2005). Antibiotics have the potential of curing small lesions and limiting surgery for larger lesions. Until this discovery, treatment largely required surgery that often involved extensive excision, sometimes with skin transplantations. But if the identification of the disease is delayed and there is an extensive necrosis of the skin or an attack on the bone the only option is extensive surgical treatment with skin grafting, and may involve amputation and protracted physiotherapy. More often there are delays in reporting on the part of patients or late identification of cases (Kibadi et al., 2009). Several factors may explain this, the main being that the occurrence of a lesion is generally painless and with no systemic symptom. As a result, in many cases the disease progresses slowly, steadily and largely unnoticed.

LITERATURE ON THE RELATIONSHIP BETWEEN BU, COPING STRATEGIES AND POVERTY

Illness is one of the most important factors associated with poverty, particularly in developing countries. Illness diminishes health status, drains incomes and impoverishes households. It is widely recognised that serious illness imposes significant adverse effects on the household labour supply and income generation. In fact, illness largely affects household income generation, food production, labour-time allocation and accumulation of productive assets, and also children's education (Ding et al., 2008). This paper forms part of a broader conceptualization of the socioeconomic consequences of BU, coping strategies households adopt and the poverty implications (Fig. 1).

The burden of an illness is often categorized into two components: economic and social. Economic burden consists of the direct cost of illness which is always seen in terms of the medical cost of treating a particular illness (cost of drugs, hospitalisation, laboratory tests, surgery, etc.), and the indirect cost which includes the opportunity cost of time lost to the patient seeking health care and the accompanying caretaker if any, and any cost of change in accommodation or dietary pattern due to the illness. Ordinarily, serious illness that involves long periods of hospitalisation requiring an accompanying caretaker would incur huge indirect cost, as these persons will be unavailable for household productivity. In several studies in Ghana and elsewhere it has been noted that the indirect cost of an illness is more than half of the total cost of that illness (Asiedu & Etuaful, 1998; Asante & Asenso-Okyere, 2003).

The social burden of illness includes reduction in labour force which causes an increase in dependency ratio to households and society at large, overreliance

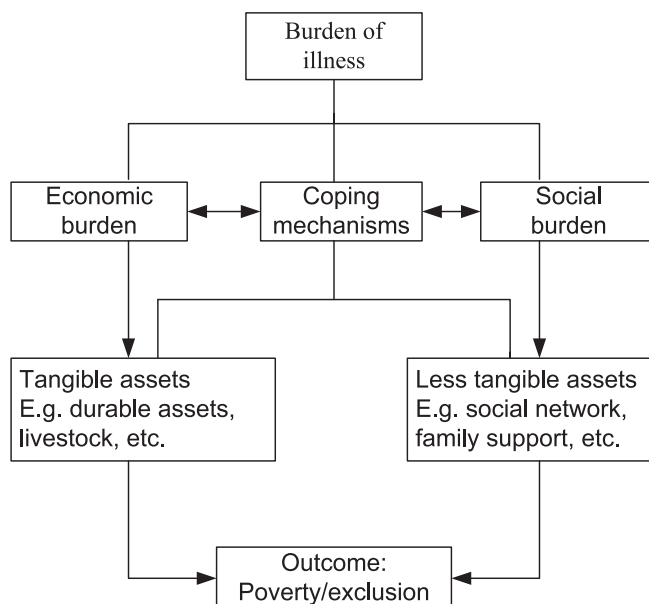


Fig. 1. Theoretical framework showing the interrelationships among the key variables of the burden of illness and households' coping strategies.

Source: Authors.

on social networks, and stigmatisation. Stigma is a very important source of social burden that is often less considered. Research has shown many diseases, such as HIV, mental illness, BU and cancer, to be highly stigmatizing, resulting in depression, anxiety, decreased quality of life, and disruption of social relationships for the affected (Awusabo-Asare & Anarfi, 1997; Stienstra et al., 2002; Weiss, 2008). Due to superstitious beliefs, afflicted persons are stigmatised in society and largely avoided or neglected. Stienstra et al. (2002) found that BU patients feel stigmatized, ashamed and embarrassed because of their infection and suffer low self-esteem.

Where the burden of illness is huge a household's viability as a socioeconomic unit is threatened. In order to sustain capability and keep livelihoods afloat, households adopt mechanisms to cope. Coping strategies are actions that aim to manage the costs of an event or process (in this case, illness) that threatens the welfare of one or more members of the household (Russell, 2004). They are strategies that seek to regain the economic viability and sustainability of the household. The burden of illness requires that households mobilise both material and non-material resources to cope. However different diseases impose different cost burdens, triggering coping strategies of different magnitude and risks to livelihood sustainability.

McIntyre and Thiede (2003) categorized illness into: mild, recurring, chronic and long term, and terminal and deteriorating illnesses. Mild illness, especially the common ones affecting households, affecting young children, could be managed through use of savings, borrowing, and temporary cuts in other spending (Russell, 1996; Sauerborn et al., 1996). For recurring illness such as malaria, a

range of strategies to manage the costs have been observed in Africa and southern Asia with intra-household labour substitution as the most common response (Asante & Asenso-Okyere, 2003; Chima et al., 2003). Chronic and long-term illness conditions such as TB impose high costs over time if regular treatment is required and if the sick are incapacitated, which lead to relatively risky coping strategies. Terminal and steadily deteriorating illness such as BU causes a process of household impoverishment through loss of income and productive asset sales.

Different strategies may also be adopted to deal with the direct costs and indirect costs (Russell, 1996; Sauerborn et al., 1996; McIntyre et al., 2006; Chuma et al., 2007; Leive & Xu, 2007). Coping strategies dealing with the direct cost of illness include borrowing, selling assets, and use of savings. Coping with the indirect cost also involves intra-household labour re-arrangements, and reduction in farm sizes, among others. Stigmatised people and their households also adopt several mechanisms to cope with the source of stigma. These may either be problem-solving (active coping styles) or emotion-focused (passive) strategies (Miller & Kaiser, 2001; Makoae et al., 2008). Emotion-focused strategies also include rationalization (such as deeming the illness same as any other illness, and saying that after all everybody will die one day), turning to God (for example, relying on prayers), and hoping (for a better turn). And problem-solving strategies include changing lifestyles, joining support groups, and seeking counselling.

The success or otherwise of the coping strategies that a household adopts depends on the resources available to the household, both tangible and intangible, which also determines the current vulnerability status of the household. The vulnerability level of a household is founded on its asset portfolio that includes tangible assets such as physical and financial capital, and less tangible assets such as education (human capital) and social resources (Russell, 2004). Social resources are the social networks on which claims can be made to obtain other resources, particularly information, opportunities, and support. These also include family and friendship networks, links to influential contacts, and membership in organizations such as credit associations.

The economic and social costs of illness and coping strategies often adopted can impact the socioeconomic outcome of a household with impoverishment a palpable possibility, sometimes even a breakdown of the household as a socioeconomic unit (Sauerborn et al., 1996; Wilkes et al., 1997). The costs that accompany BU treatment, its disabling outcomes, coupled with its associated stigma are capable of starting a process of household impoverishment. BU disability leads to loss of productive man-hours and loss of income. This means that BU is likely to force affected households to adopt risky coping strategies such as consumption cuts, premature productive asset sales or irrational borrowing leading to high levels of debt. A household's capacity to cope with BU can be further undermined because its associated stigma generates social exclusion and results in weakened support networks (Boleira et al., 2010; WHO, 2010). The coping strategies discussed above have been already noted to be potentially risky for the future welfare of households (Russell 1996; Wilkes et al., 1997). Coping strategies such as sale of assets can lead to asset depletion and asset poverty, while repayment of loans with high interest rates can lead to inescapable debt burden on the household.

Prejudice can increase people's anxiety and affect the quantity and quality of health care they receive (Allison, 1998; Clark et al., 1999). Disease stigmatisation has an intricate link with health-seeking behaviour, and impacts heavily on the costs outturns and treatment outcomes (Brown et al., 2001). Due to the social interpretations given to certain diseases, persons affected tend to avoid people, as they may initially choose treatment strategies involving use of herbs, self-medication, and purchase of drugs over the counter (Awusabo-Asare & Anarfi, 1997). This tendency leads to delays in reporting the infection for early attention thus enlarging the enormity of coping that is required. Hoffman (1996) indeed noted that, the relationships between health status, stigma, and ways of coping for HIV infection was inherently stressful and had a major influence on quality of life.

Conceptualizing the discussion involving coping mechanisms may be complex, but it is important in helping us appreciate in a more comprehensive manner how BU affects people, impoverishes households and perpetuates poverty. While there is some information on the burden of BU in Ghana, there is very little discussion of how households mobilise resource (material, human and intangible) to cope with the burden of the disease. In this paper we review the burden of BU on households and discuss more particularly the coping strategies that households adopt to deal with the socioeconomic burden of the disease including stigma that has not received much attention. We hope to expand knowledge on the burden of BU and contribute to major discussions on how households cope with illness in developing countries.

STUDY AREA AND DATA SOURCE

The Ga West District, in which the study was conducted, has an estimated population size of about 473,835 (with a growth rate of 3.4 percent in the 2,000 Population and Housing Census, the most recent for Ghana). The population density is estimated to be about 667 persons per sq km. This gives an indication of the great population pressure on land resources. The population under age 15 is 34.8 percent, while that of the elderly is 3.0 percent, a reflection of high fertility and low life expectancy. This is typical of less developed economies that are normally characterized by a large proportion of children (under age 15) and a small proportion of elderly persons (over age 64).

The major economic activity of the Ga West District is farming. About 70 percent of the people are engaged in agriculture. Other economic activities include fishing, stone quarrying and petty trade. There are eight health facilities in the district: two in Amasaman, the district capital; four in Weija, one in Obom, and one in Mayira. Other health centres located in Oduman and Ngleshie Amanfro serve a considerable portion of the rural population of the district. These are mainly provided by the government, although there are a number of private clinics and family planning and maternity homes. Health care to the rural communities is mostly provided by the Ghana Health Service through monthly outreach services.

Among the top five common diseases prevalent in the District are malaria, skin diseases, diarrhoea, HIV/AIDS, and BU. The district has the highest number of

reported BU cases in the Greater Accra Region. Again, the district is the fifth most BU endemic district in the country. A study by Amofah and others (2002) using 1999 data indicated that the prevalence rate of BU in the Ga West District is 87.7 per 100,000. BU treatment is free of medical charge in Ghana. The District Health Centre at Amasaman has a specialized unit for BU cases. But most of the indigenous communities in the district lack access to quality health care in the district. The distribution of health facilities is poor relative to the number of communities that have high prevalence of BU. These areas include Konkon, Alfia and Awudiana, Obom and Bibianiha. This raises the problem of access to health care for the majority of the population, which has implications for health seeking behaviour, indirect cost of health care, and coping strategies.

I. Data

The study dealt only with persons who received treatment from the Amasaman Health Centre (the only referral clinic for BU in the district, hereafter DHC). This is because we wanted only the confirmed cases for the study. We also wanted to keep the recall period reasonably within memorable limits, so the study was limited to persons who were registered and treated within a period of one year or less (2007/2008). The respondents were chosen essentially to help us highlight the other burden of BU, as medical care for patients were free at the DHC. We recognize that quite many patients do not choose the hospital for treatment but rather prefer to self-medicate or visit herbalists. The services of the latter may not necessarily be cheaper. But locating such people for this study was not practical due to the very reason of non-reporting because of stigmatization. We therefore note this difficulty as a limitation of our study.

At the time of this study, the DHC had discharged 103 BU patients. Five persons could not be traced due to relocation outside the district. Twelve persons were excluded because their treatment extended over one year. There were persons who came for treatment, but for one reason or another abandoned the treatment only to report later with serious necrotising sores. Data were therefore collected from 86 patients who received treatment within a period of a year or less. The primary caretaker/head of household was interviewed if the patient was a minor (under age 15).

The Amasaman Health Centre (DHC), the only referral unit for hospitalising and treating BU in the district, keeps detail records of persons and their treatments. We relied on these records for information on affected households and communities, which aided us in locating the interviewees. World Vision International (WVI), an international non-governmental organisation in Ghana with an office in the district also runs outreach programmes on BU. They educate communities, identify and help direct the BU stricken to the DHC for care. WVI also keeps detailed records of all the cases. These records were made available to the researchers to help locate respondents, except for those who had moved out of the communities.

A semi-structured questionnaire with room for qualitative answers was the main instrument used in collecting data for this study. We also collected information

on incomes of household members (reported incomes). For strictly agriculture- and peasant agriculture-dependent households, we estimated the total value of their farm produce using the prevailing market prices at the time. We, however, wish to note the practical difficulties, such as self-bias on consumption and other unaccounted for expenditures, as minor limitations. We complemented our data with an in-depth interview with the officer in-charge of health services at WVI. The interview was intended to identify the various intervention activities as far as treatment of BU in the district was concerned.

Our findings in this study, however, are coloured by additional limitations of our methodology. As stated above, these include the dependence on hospital records for our sample selection, and the use of a convenient sample. These do not make room for external validity of our findings.

RESULTS

I. Socio-Demographic Background of Study Population

The mean annual reported income of a typical household in the district was GH¢490.70 with an annual per capita income of GH¢98. During the time of data collection, the Ghana cedi (GH¢) had about the same value as the United States dollar. This per capita income is extremely below the poverty line. Large proportions (94.2%) of BU victims reside in the rural part of the district. About 22.1 percent of the BU affected persons are farmers, but more than 60 percent (61.6%) of them come from agriculture-dependent households. About 57 percent of the affected persons were pupils/students and 7 percent were unemployed. Most of the BU affected persons were largely less educated with just 2.3 percent completing tertiary education, while 33.7% had received or were receiving primary education. Nearly 34 percent had no education at all (Table 1).

There was no variation in the sex distribution of the infected patients. Females (49%) were nearly equally infected as males (51%). About 49 percent (48.8%) of those infected were below 15 years old, and approximately 51 percent of the rest were above 17 years. About 30.2 percent were children between the ages of one and 10, and 18.6 percent were between the ages of 11 and 15. Most of the infected children were school age, which meant for them, a disruption of formal schooling, at least for a period of time.

SOCIOECONOMIC BURDEN OF BU

I. Time Lost in the Course of Seeking Treatment for BU

Treatment at the DHC did not incur any direct cost since medical cost was free of charge. World Vision International (WVI) also provided for most of the cost of other medical services to the patients, including laboratory examinations, surgery, and amputations. WVI also provided a facility located near the Health

Table 1. Socio-demographic characteristics of BU patients interviewed

Variable	Attribute	Percentage
Sex distribution	Male	51.2
	Female	48.8
Age distribution	1–10	30.2
	11–15	18.6
	16–35	31.4
	36–65	19.8
Educational level reached	None	31.4
	Primary	33.7
	JSS/MLSC*	18.6
	Sec/tech	11.6
	Tertiary	2.3
Occupational status	Farmer	22.1
	Trader	5.9
	Gov. employee	2.3
	Driver	3.5
	Carpenter/mason	2.3
	Pupil/student	57
	Unemployed	7
Locality of household	Urban	5.8
	Rural	94.2

Source: Authors' survey, 2008.

*JSS/MLSC means Junior Secondary School/Middle School Leaving Certificate.

Centre for accommodation, and paid for transportation of most patients who travelled from afar to the hospital for sore dressing. Notwithstanding, there remains a cost that households still have to bear. Due to the in-hospital treatment model (directly observable treatment system, DOTS), individuals and households lose manpower and labour-time to hospitalisation. A household may lose two persons, the patient and the caretaker.

Treatment of the disease at the DHC involves about eight weeks of mandatory hospitalisation to receive the 8 week antibiotic treatment under the DOTS method recommended by the WHO (2004). After eight weeks, patients whose conditions are severe (plague, oedema and ulcers) in need of surgery are further hospitalised. In all, a total of 17,661 days was spent on treatment for all the cases studied. The average patient spent a total of 205 days for treatment at the DHC including hospitalisation and time as an outpatient receiving sore dressing. The mean for hospitalisation days was 167. In addition, a patient spent on average approximately 33 days for review and sore dressing. A patient was likely to lose a total of approximately 180 days for treatment.

The number of days spent receiving treatment varied according to the severity of the condition presented at the DHC (Fig. 2). A patient could stay far longer than the standard eight-week period. The total number of days a patient with a nodule was hospitalised was approximately 74 (73.67). The average a patient with a nodule was hospitalised was 67 (66.67) days and spent a minimal number of

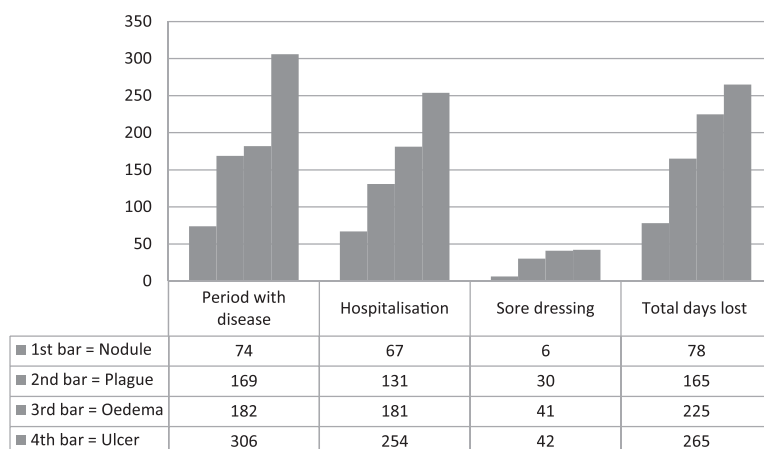


Fig. 2. Days spent receiving treatment and workdays lost.
Source: Authors' survey, 2008.

6 days for sore dressing, and was likely to lose 78 (77.89) days of productive work time. This count differs quite markedly from that for a patient in ulcerating stage. An ulcer patient spent a total of 301 days receiving treatment at the DHC, hospitalised for nearly 251 (250.52) days, visited 44 days to receive wound dressing, and probably lost 265 (264.5) days of productive work time.

A patient with a plague spent approximately 169 days for treatment: hospitalised for 131 days, visited 30 times for sore dressing, and was most likely to lose 165 days of productive work days. A patient in the oedematous stage spent 182 days for treatment, and was also likely to have been hospitalised for 182 days. They spent 41 days for sore dressing and were more likely to lose 225 of productive workdays for treatment.

In all of the cases a patient was accompanied by a caretaker or visited by a relative or a friend. If the patient was a child, a caretaker stayed along to provide basic needs for the patient. Many caretakers lost on the average, about four (4) days out of a week taking care of a patient at the hospital, unable to attend to their usual activities. In about two percent (2.1%) of cases, caretakers lost nearly a whole week (6 days) taking care of their child (Fig. 3). Most often these caretakers were mother/father, husband/wife, son/daughter, brother/sister, and other relatives or friends (see appendix).

II. Problem of Loss to Labour Force

Closely related to the loss of time/workdays is the loss of labour for the household. As can be deduced from the foregoing, the occurrence of BU and its hospital-based treatment option involves a decline in the household's labour force for productive activities. The household suffers two losses: the household's own labour force and the ability to mobilise communal labour. If BU strikes an economically active person, the household loses his or her contribution in production. And where the person who visits/and or mostly tends to the sick person is yet

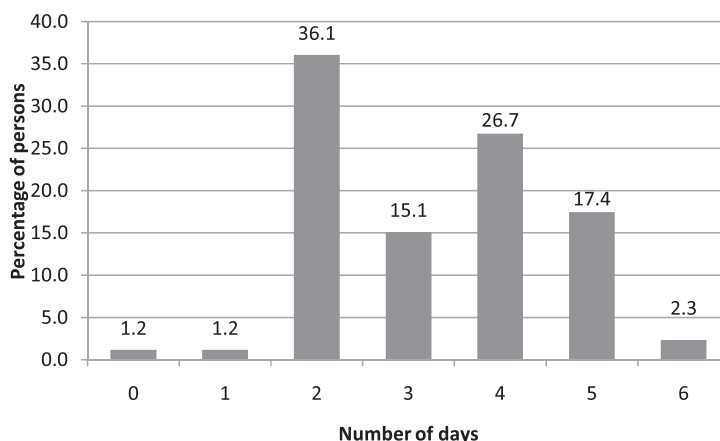


Fig. 3. Number of workdays lost by caretaker accompanying/visiting a BU patient.
Source: Authors' survey, 2008.

another economically active person, then such a household loses the labour force contribution of two persons to the disease. This can also be looked at in terms of workdays lost by both the sick person and the caretaker.

The above second labour loss has to do with the stigma and the prejudice associated with the BU. Four households said they needed support with communal labour but were unable to mobilise such needed assistance. In one instance a household head complained that he was not able to get help to re-erect his thatched-roof when it was blown off by the wind. It took the assistance of his extended family to help reroof his dwelling.

III. The Burden of Stigma

Respondents were also asked whether they suffered or perceived any change in attitude or behaviour of people towards them or their households since their illness became public knowledge. About 62 percent of the respondents (53 patients and parents/caretakers) answered in the affirmative, suggesting that they had suffered or were suffering a real or perceived negative change in attitude towards them. Five people thought they lost their marriages and were divorced due to BU. Over 60 percent of those who responded that they noticed a change in behaviour in people towards them said people avoided their company (Fig. 4). Nearly 20 percent noted that people gossiped about them, and more than 10 percent indicated that they had lost respect in the eyes of people because of BU. About eight percent of them thought they were dismissed from their jobs because of BU.

Those who complained of being avoided indicated that they no longer could sit and have conversation with friends. Parents whose wards had the disease also said they were avoided and gossiped about. Although the respondents were not sure what the gossip was about, they still suspected quite strongly that people talked about them.

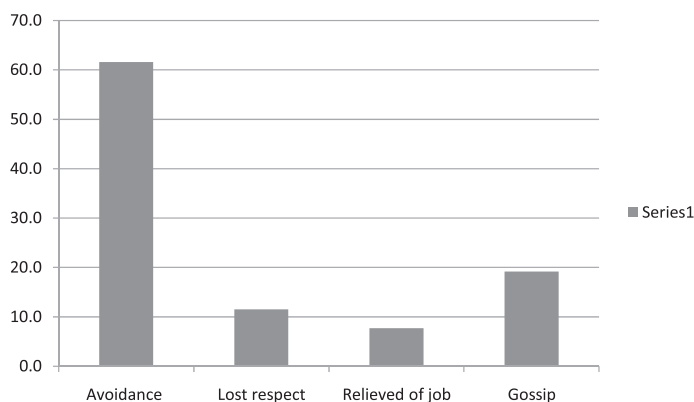


Fig. 4. Patients/household heads who noticed a changed attitude towards them (%).
Source: Authors' survey, 2008. A total of 53 patients/respondents.

Generally, men felt more stigmatised than women. More than 50 percent of those who reported having suffered one form of stigma or the other were men. But in terms of those who felt that they were gossiped about, 80 percent were women. All the persons who suffered marital separation or divorce were also women. In fact, one woman said she was driven away by her husband aided by his family members. In terms of respect, more men than women felt that they had lost respect in the eyes of people (83.3%).

COPING WITH THE BURDEN OF BU

We found three distinct sources of need for coping with the burden of the disease: the economic cost (medical cost) of treatment, the loss of labour, and stigma associated with the disease.

I. Coping with the Medical Cost of Treatment

In establishing the strategies adopted by households to cope with the economic cost of the disease, respondents (patients/adult caretakers/heads of households) were first asked how they paid for the cost of treatment. Although treatment is free at the DHC, it was still important to identify among other things, possible under-the-counter payments for the otherwise free treatment programme. Respondents indeed confirmed the treatment at the DHC to be free, so they did not spend anything on their own on medical care indicating no under-the-counter payment. However, the study found that WVI was another principal benefactor of the free treatment programme in the district.

WVI shoulders most of the cost related to laboratory investigations, surgical operations and amputations, according to the officer in-charge of WVI, Ga West District Office Health Outreach Programme. Again, WVI provides wheel-chairs and prosthesis to the BU patients as necessary. The NGO reimburses the transportation fare of most of the patients to and from the DHC for treatment. One

WVI programme officer noted that the situation of BU victims in this district was pathetic:

“Some of them are not able to commute to the health facility for lesion dressing after surgery. So we encourage them to come by paying their transport fare for them. Sadly, anytime we are unable to give them the transport fare some will not come the following day.” (Officer in-charge, WVI, Ga West District Office, Health Outreach Programme.)

The respondents recognized the role of WVI in making access possible for them to benefit from the free treatment programme at the DHC. One said:

“If it were not for World Vision, I would not have been able to commute to and from the DHC for this treatment. When this sickness became serious I could not farm again, I lost everything. I sold a lot of my sheep and even my bicycle that I ride to my farm.” (A 56 year old man from Abom, a rural area with a high prevalence of BU in the district.)

The WVI provides meals to patients, their caretakers and immediate family members, and stage-at-school appropriate lessons for children of sick parents or afflicted children. These school lessons are offered in structures provided by the NGO close to the hospital. Incidentally, WVI was scheduled to fold its BU intervention programme in 2008, the year of data collection.

Use of savings: For respondents who incurred medical cost as a result of seeking treatment from herbalists, private clinics, drug stores and other forms of self-medication, the most predominant source of cash was the use of their savings (Table 2). Savings here included bank savings, savings with private microfinance groups, known locally as *Susu*, and stored food stuffs. Due to the rural nature of the district, banks are only available in the district capital, Amasaman, and Weija, one sub-district capital. The people are largely served by credit union operators and local *Susu* collectors. In majority of cases the use of *Susu* savings was the main source of cash for payment of treatment cost. Sale of foodstuffs was used largely by people who did not have any form of financial savings or those who may have exhausted their *Susu* savings.

Family support: Family support was the second most prominent source of cash for payment of non-free treatment cost. The family network system is extremely important and quite prominent in the rural areas in Ghana. More than 17 percent of cases received financial assistance from extended family members. Normally, financial assistance from family members is either not repaid or repaid with no interest. Family support was, however, not always the immediate line of action for financial assistance. This was because of the stigma associated with BU, and so people exploited this option when other options were exhausted or had failed.

Sale of assets: Sale of assets was another strategy that individuals or households used to pay for the cost of treatment of the disease. Nearly a third of households studied (26.7%) sold off assets. Major household assets sold included livestock, land, and other durable items. Livestock was the most commonly sold.

Only one patient sold land to pay for BU treatment at a private clinic where the household started receiving medical care for the disease.

Borrowing: About 16.3 percent of the households we studied borrowed or took loans to pay for the non-free treatment cost. We found that it was more common for the respondents in the urban areas to take out a loan or borrow money to manage the treatment-related expenses than was the case in the rural areas. The number of respondents who borrowed money to take care of the treatment-related expenses in the urban areas were nearly twice as many as those who borrowed money for the same purpose in the rural areas.

II. Coping with Loss of Labour

Family support: This was a very prominent strategy for coping with the unavailability of a household member due to sickness. Over 37 percent of households relied on family for labour. The family support was in two forms: as caretakers to the sick person and as labour for farm work. BU treatment can straddle over a farming season (normally half a year). A very important source of labour for farm work, especially in rural areas, is mobilisation of communal labour. But because of the stigma associated with BU, all above-mentioned four patients and their households who needed communal support could not get it. Support from the extended family was the only option available to such people. In 13 percent of cases, school-going children were withdrawn or took leave from school to accompany the sick to hospital or take care of the house while a parent was hospitalised.

Reduced size of farm: Another strategy that BU affected households chose to cope with the absence of an adult member was to reduce the size of their farms. About 23 percent of those interviewed indicated that they had done so. Two reasons informed the adoption of this strategy. The first reason has to do with the fact that people perceived the cause of the disease to be associated with their farming environment (marshy places, especially in the valleys). As a result, some people abandoned their farms in such locations that they presumed to contain the organism of infection. And the second reason is intuitively obvious, that as the labour force of the household was reduced, the ability of the household to cultivate the original size of their farm became challenged. This coping strategy is potentially risky and poses tremendous challenge for poverty reduction.

Hired labour: Some households, nearly 21 percent of households studied, hired labour. Those who hired labour were the few relatively wealthy people with pineapple farms and palm plantations. While it is difficult for BU victims to mobilise communal labour (normally free in the study communities), it is not so difficult to buy labour from casual labourers. Most of the casual labourers hired were people from different parts of the district or other parts of the country, who trekked about in farming communities in search of farming jobs. They are normally a good source of labour, especially for well-to-do persons in the rural farming areas.

III. Coping with Stigma Associated with BU

The life of a BU infected person, including the entire household, is a constant struggle not only to manage the cost of treating the disease but also to cope with stigma associated with it. BU infection is associated with prejudice about its cause. This engenders much stigma that people have to cope with, sometimes for life. The strategies commonly adopted by individuals and households to cope with this phenomenon were largely emotional and psychological.

Avoidance: The main coping strategy that people adopted was avoiding the source of stigma. Common statements from such people included:

“If people do not want your company, you don’t even go near them. For example, I don’t attend community meetings and programmes such as child-naming ceremonies. Besides they will not even want me there.” (Rural, BU infected woman.)

Religiosity: This strategy focused on spirituality. It included activities such as praying to God and believing that one will get healthy and strong again. The respondents who focused on religion as a coping strategy used solely the church for socialization. Traditional religious practitioners and their followers typically believed in retribution and consoled themselves with the belief that people who despise them will not be spared one day.

Ignoring others: Others also adopt the attitude of, “I don’t care what people say or how they behave towards me. Every illness is the work of God. Anybody can get this disease so I don’t care what people say. I know it will go one day.”

Table 2. Coping strategies adopted by households (%)

Coping strategies	Medical cost	Loss of labour
Family support	17.5	37.2
Hired labour		20.9
Sold assets	17.4	9.3
Used savings	53.4	
Borrowed	10.5	5.8
Friends	1.1	3.6
Reduced farm size		23.2

Source: Authors’ survey, 2008.

DISCUSSION AND IMPLICATION FOR POVERTY AND POVERTY REDUCTION

BU has always existed, yet until recently, people gave very little attention to it. It is a slow, steady and secret disease. When unnoticed for a long time it eats the flesh of its victims and destabilise the resources of households. BU is in fact advancing faster today and the number of affected people is increasing world-wide. No wonder the World Health Assembly declared it a threat to world health and an impediment in the achievement of UN Millennium Development Goals in

the year 2004. This is because the socioeconomic and physical harm it causes to individuals and families is harsh. The disease does not kill, but cripples victims and dislodges their household economies.

The Ga West District is predominantly agriculture-dependent and people are largely engaged in farming as indicated in the proportion of infected persons who are farmers. The second point is that, most of the infected persons live and farm along the Densu, Ntafrafra, Onyasia, Nsaki, Honi and Adaiso valleys. This was also found in an earlier study by Kofie (2000), who noted a preponderance of cases along these same areas. Farms are mostly found in the valleys, where farmers work with their feet stuck in the muddy and swampy environment. Females and children may contract BU through fetching water from the riverside or streams, which is a very common source of water for household use in the rural areas.

BU may not afflict so many people in a community, but its consequences, both economic and social, is infectious. As shown in this paper, treatment of the disease is burdensome, both economically and socially. The cost of treatment in terms of time and loss of labour is economically disabling. We confirmed Stienstra et al.'s (2002) findings that many people resorted to treatment from traditional healers, herbalists, engaged in self-medication, or purchased non-prescription drugs to treat the disease before reporting to the health facility when all else had failed to work. Because of these series of first line of treatment attempts, there are delays in having the disease treated early.

The value of time lost to hospitalisation and travelling to and from the hospital for care is huge. The mandatory hospital stay alone is a source of enormous time cost to households. In many cases households lost two active household members to BU treatment, as one is required to accompany the patient or regularly visit them at the hospital. On the average, the studied households lost more than half a year under treatment at the DHC, including hospitalisation and wound dressing. Caregivers lost at least half a week visiting or taking care of the hospitalised. In the end, total opportunity cost of time lost is several times higher than the medical cost of treatment (Asiedu & Etuaful, 1998).

Individuals and their household members also have to contend with the burden of societal prejudice. Individual victims and their relations live through the trauma of gossip and prejudice, as many people associate the cause of BU with witchcraft or a curse from God (Stienstra et al., 2002). This burden may even be weightier than the economic cost of the disease. There is a widespread and misinformed belief among indigenous communities that one contracts BU by being cursed or was inflicted by their enemies in the society, and he or she may actually deserve this "self-inflicted" condition. Such beliefs cause further social burden of suffering avoidance by colleagues, loss of respect, and being gossiped about. Several respondents indicated that they were normally avoided by even their closest friends, and marriages have broken. This societal perception also affected some households' ability to mobilise communal labour for farm work or other family activities, a common practice in the rural areas. Communal direct cooperation among community members to make available their labour and time to support a community member is a particularly important source of support in rural agrarian communities. The shame and the stigma that accompanies BU are detrimental for the patient

to accept the disease as just any biomedical illness. This negativity affects the peoples' preparedness to report for treatment.

In the midst of all these, households are clearly confronted with the opportunity cost of unavailable labour. The family support system is the primary and highly resorted to source of coping with the burden of BU. Family assistance is extremely essential, because it builds and strengthens social networks. One can never tell when misfortune may befall. It is important to note that in the Ghanaian cultural setting, one's wealth is not determined solely by his or her material assets, but also by one's social capital. Indeed, social network forms an integral component of the asset base of a household (DFID, 2000).

Another direct cost to households with BU patients is the cost of transportation. In the study district most of the indigenous communities are in remote rural areas where roads to the district capital where free treatment is available do not exist or are unmotorable most of the year. Most rural communities are serviced by just one minibus scheduled to come and go not more than twice a day, usually in the morning and evening. Non-hospitalised BU patients had to commute to the district capital for care every day, especially for wound dressing. With WVI set to close their program for BU, an enormous gap has to be filled.

Normally, households build assets of all forms primarily as a form of security for future use. Livestock for instance are considered a store of wealth among rural households in Ghana (Aryeetey, 2004). When illness strikes, households commonly sell livestock first. Sale of durable household items such as television, furniture, and other utensils was not common among our respondents, because sale of these items amounts to a too obvious "failed state of the household's adaptive capacity." In the Ghanaian society, it is indeed very disgraceful to be seen selling your family television or furniture to seek medical care.

Reliance on loans from banks, other financial institutions, and individual lenders is another major source for coping with the burden of illness. In the event that the sale of livestock is not able to adequately cover the medical cost, the next source of cash is either family members (for the rural household), or the bank or friends (for the urban households). In the rural setting where everyone knows everybody else, rural people largely feel a sense of shame to borrow from friends. So they prefer to seek support from the family networks as compared to the urban residents whose family networks are weaker. Although a comparatively lesser proportion of our respondents resorted to this strategy for handling the economic cost of being affected by BU, in Ghana, taking out loans for resolving economic crisis at the individual or household level is perceived to reflect a shaky, and therefore shameful economic condition of the household.

Our finding that the afflicted households in the urban areas were more likely to borrow money as a means of coping with the economic effect of BU may be for three main reasons. The first reason was that financial services such as banks and microfinance institutions are more available and accessible in urban areas in Ghana than in the rural areas. Hence, it is easier to get financial resources to borrow in the urban areas than in the rural areas where people largely save in the form of livestock. Secondly, support from the extended family is stronger in the rural areas than in the urban areas. Hence rural households tend to receive

financial assistance from family members that cushions them beyond the need to borrow. Thirdly, borrowing from friends is perceived to be disgraceful in the rural areas. Rural residents prefer relying on family ties to borrowing from friends.

I. Implication for Poverty Reduction

BU treatment at the DHC may be free of charge, but this is only comforting in the short term. The impact of the disease in the long run defies poverty reduction efforts. BU may not be as devastating as HIV/AIDS, but the degree to which it draws one closer to poverty is more acute than HIV. Perhaps not only because its treatment is very costly, but also because more often than not victims come out of treatment with limited functional limbs (sometimes with amputations). Such people are unable to work, thus becoming liabilities on households and increasing the dependency burden to the society. The long periods of hospitalisation resulting in loss of active labour is sometimes accompanied by another loss as caregiver. When this situation straddles more than one agriculture season, coupled with an inability to mobilise communal labour, it means a reduction in the labour force of the household, and reduction in the cultivated land of the household. The implication of this for the future is a reduction in farm output and a subsequent threat to food security.

If we further concede that BU largely affects children (Asiedu & Etuaful, 1998; Amofah et al., 2002; Kofie et al., 2008) most probably in school, we appreciate more intensely the future poverty implications of BU. Children are affected in two main ways: first as patients and second as caregivers. But the sources of future poverty can be seen in three ways. First, if children are afflicted, then they are likely to suffer disruption of schooling due to the prolonged morbidity of BU treatment. Secondly, complications such as amputations and contracture deformities common among children will mean that the children will be disabled to work (Asiedu & Etuaful, 1998). These children will grow into adulthood and may become a burden on society. Thirdly, as caregivers, children also encounter disruption of formal education in the process, but more worrying, they are sometimes made family heads before they have the chance to grow, if the adult breadwinner is incapacitated by BU. This affects their growth and general preparedness for life.

BU may be costly to treat (in terms of medical, time and related opportunity costs), but it is even more burdensome to cope with after a substantial amount of the households' resources have been depleted, and even more stressful as it is associated with much cultural or societal prejudice. Most of the strategies households adopt to cope with the economic cost of the disease are often unsustainable and poverty inducing. The use of personal or household savings may not be problematic, but sale of assets may lead to asset depletion. This increases the vulnerability level of such households and deepens their level of poverty. Besides where the sale of assets involves productive assets (livestock such as bullocks, donkeys, farm equipment, etc.) the opportunity cost can be very high. This harms the future capacity of the household to accumulate or build wealth and their descent to poverty can be unpreventable.

BU related stigma has tremendous negative effects on treatment-seeking behaviour. There is a constant struggle by BU infected persons and their households to cope with the stigma associated with the disease. The attitude that individuals and households adopt in managing their BU status with others is rather undesirable. Avoiding people and choosing to hide from people rather perpetuates the stigma. Miller and Kaiser (2001) noted that avoiding highly prejudiced people may be an excellent strategy, if the stigmatised person has little to gain by interacting with these people. But in this case the infected person may need the communal assistance of community members on their farms and other areas. Clearly this is not a sustainable coping strategy. People are prejudiced about something largely because they have very little information about it. It rather pays for the one with enough experience of that thing to deflate people's bigotry by helping them know more through words and actions. A household's vulnerability to poverty may be increased if the chosen responses restrict the options available to protect against subsequent difficulty. Given all the above-stated economic and related costs of BU, we recommend that households in the district which have been affected by BU be enrolled in social protection programmes such as the Livelihood Empowerment Against Poverty (LEAP) programme, and be considered as indigenes under the National Health Insurance Scheme.

Clearly BU infection is economically burdensome and socially stigmatising. And it is stressful to have to cope with this burden. Whatever the chosen coping strategy, there is invariably income loss to the household. The relationship between health status, burden of care, and ways of coping are therefore complex but important. The relationship is particularly important for understanding how health is connected to poverty. Even without any complex econometric modelling to determine causal relationships, we can still convince ourselves that the BU infection, the magnitude of its economic burden, and the coping strategies that a household has to seek have serious implications for future poverty outcomes.

CONCLUSION

Although a major impediment to poverty reduction, especially in the rural areas where agriculture is the mainstay of the population, very little may be known about Buruli Ulcer even if it may have existed for several centuries. Our study which focused on the coping strategies the infected and affected persons use revealed great economic, labour, stigma and direct and indirect medical costs, all of which the victims and their households must contend with, informed by the cultural setting where they live. The opportunity costs associated with the burden of the disease may never be aptly quantified. BU also engenders many psychological, emotional, cognitive and behavioural scars. How the affected persons and/or their households cope with the disease burden should be of interest to policy makers since it undoubtedly affects productivity and poverty reduction efforts. We recommend that BU affected households in the district be covered by social protection programmes such as the LEAP.

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APPENDIX

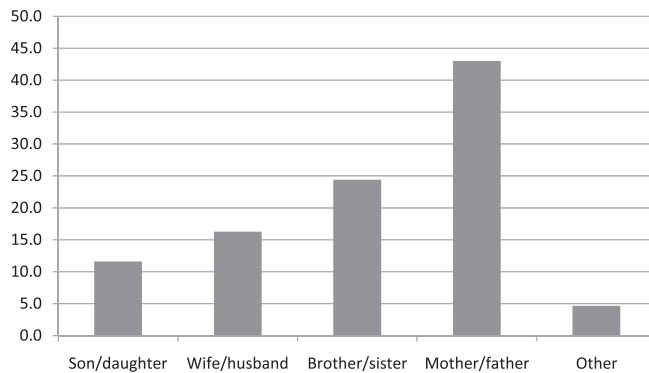


Fig. A1. Persons who attended as caretakers/visited patients at the hospital (%).
Source: Authors' survey, 2008.

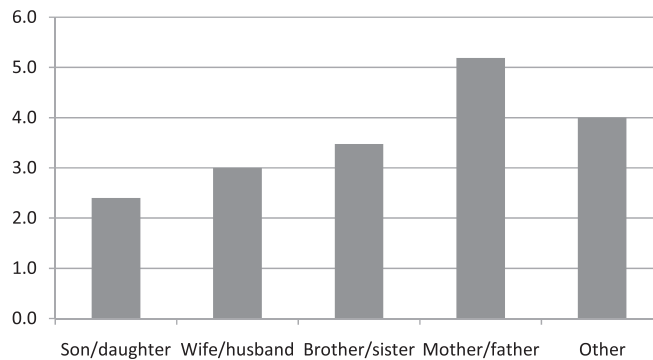


Fig. A2. Number of times a week the caretaker/visitor attended patient at the hospital.
Source: Authors' survey, 2008.